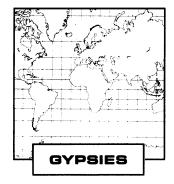
- Gypsies, widely distributed throughout Europe, migrated to the United States at the end of the 19th century
- It is estimated that there are between 200,000 and 500,000 Gypsies in the US
- There are several culturally distinct groups, of which the Rom is the largest



# Cross-cultural Medicine A Decade Later

## **Gypsies and Health Care**

ANNE SUTHERLAND, PhD, St Paul, Minnesota

Gypsies in the United States are not a healthy group. They have a high incidence of heart disease, diabetes mellitus, and hypertension. When they seek medical care, Gypsies often come into conflict with medical personnel who find their behavior confusing, demanding, and chaotic. For their part, Gypsies are often suspicious of non-Gypsy people and institutions, viewing them as a source of disease and uncleanliness. Gypsy ideas about health and illness are closely related to notions of good and bad fortune, purity and impurity, and inclusion and exclusion from the group. These basic concepts affect everyday life, including the way Gypsies deal with eating and washing, physicians and hospitals, the diagnosis of illness, shopping around for cures, and coping with birth and death.

(Sutherland A: Gypsies and health care, In Cross-cultural Medicine [Special Issue]. West J Med 1992 Sep; 157:276-280)

ypsies are a largely unknown ethnic population in the JUnited States. Lacking census data, most estimates suggest there are between 200,000 and 500,000 members of various Gypsy groups living in all regions of the United States. Not all Gypsies belong to the same group or speak the same dialect or language. The data presented here refer to the largest group, the Rom, which is the group physicians are most likely to see and to recognize as Gypsy. The Rom live all over the United States. The specific group this article is based on live in the San Francisco Bay Area of California. The Rom are originally from India, migrated through the Middle East and Europe over the past 800 years, and arrived in the United States primarily at the end of the 19th century. The Rom speak Romany as a first language and English as a second language. Older Rom are generally not literate, but younger members of the family usually have some schooling and can read important documents to older members.

Although most Americans hardly know that Gypsies live in their cities, the medical profession is usually aware of them. This is because Gypsies are generally not healthy and because they are assertive in seeking medical care. Gypsies have an unusual ability to maneuver within a complex medical system and to get attention from medical personnel. The Gypsy "style" of seeking help is often frustrating and confusing to health care professionals. Gypsies often request specific "famous name" physicians and demand specific treatment they have heard of even when the treatment or specific physician is inappropriate. Gypsies frequently request specific colored pills that they share with their relatives. They prefer older, "big" (well-known) physicians over younger ones. They often do not comply with preventive and long-term treatment. When a relative is sick, they come to the hospital in alarmingly large numbers, sometimes camp on hospital grounds, disregard visiting rules, and generally create chaos in the corridors of the hospital. Hospital personnel are often at a loss in knowing how to deal with Gypsies.

Gypsies can be cooperative, interesting patients, however. They respect authority in their own families, they are eager to learn about the best treatment for themselves and their relatives, and they have a large support network of relatives. All of these factors can be called on by medical professionals to assist them in providing treatment to Gypsies while reducing the disruption that results from a sick Gypsy's desire to have relatives nearby.

In this article I provide information about Gypsy culture that will be useful for understanding how to interact with them in medical situations. This article contains guidelines, but not every Gypsy follows every single custom or rule. Families and individual members have varied practices. Some Gypsies are more old-fashioned than others; some are more fastidious; some, generally older ones, are more informed; and some are sicker and have more experience with physicians. Nonetheless, these general guidelines should ease some of the frustration between Gypsy patients and health professionals.

#### **Gypsy Culture**

Gypsies live in urban areas, usually on main streets, in the poorer parts of towns. They are not always recognizable as such, especially the men who wear American clothes; however, women, in particular older women, often wear long colorful skirts and low-cut sleeveless blouses. Gypsies often prefer to pass as another ethnic group and may claim to be American Indian, Mexican, or Romanian. They are accustomed to discrimination and stereotyping by those who often see them either romantically as free spirits or as contemptible thieves. Neither stereotype is accurate. If a medical professional indicates that it would help to know if a patient is Gypsy, the family may freely admit to it.

Gypsies live in households with somewhat fluid member-

ship because they generally belong to large extended families. Dating back to the days when they all shared one camp, members of extended families will eat and sleep at each other's homes as if they were their own. The men work in groups of relatives and friends. Their usual work involves soliciting body and fender repair jobs, buying and selling cars, or helping women with their fortune-telling businesses. The women (mothers, daughters, and daughters-in-law) often share a storefront office or room at the front of a house, where they tell fortunes. Gypsies prefer to keep to themselves and to avoid contact with non-Gypsies. As a cultural group, they have survived hundreds of years living by their wits.

#### Illness Is Social

For Gypsies, illness is not just the concern of the individual, it is a problem of broader social importance. A serious illness always elicits deep concern from a wide circle of relatives willing to drop everything and rush to the bedside of the stricken. The gathering of Gypsies in the vicinity of a seriously ill person is partly socially mandated by custom but also is a genuine expression of concern for both the afflicted and his or her immediate relatives. Families coming together when someone is ill is one of the strongest values in Gypsy culture.

A knowledge of certain basic beliefs and behaviors of Gypsies in relation to sickness and health and the sociocultural context of health care is essential to effectively interact

Positive Concepts	Negative Concepts
Romania (social order)	
Rom (Gypsy)	Gaje (non-Gypsy)
Traveling	
Sastimos (good health)	Naswalemos (illness)
	Prikaza (bad luck)
Wuzho (purity)	Marime (impurity; exclusion)

with Gypsies. The social context of Gypsy medical and religious knowledge begins with Gypsy attitudes in general toward health and illness, auspiciousness and inauspiciousness, and cleanliness and uncleanliness.<sup>2</sup> These attitudes are reflected in certain key concepts, presented in complementary opposition in Table 1.

#### Fortune and Health

Good fortune and good health are closely associated for Gypsies, as expressed in their most common blessing, "May God give you luck and health." Those who enjoy good health also have been blessed with good fortune; those who are ill have lost their good luck. To some extent everyone can influence their own fortunes. By their actions they either promote their own health or cause their own illness. Illness can be caused by actions that are considered contaminating or polluting. Returning to a state of purity and conforming to correct social behavior are necessary to cure these conditions. For example, a young person who exhibits rebellious behavior and may be in danger of pollution through illicit sexual relations can be "cured" by marriage.

Perhaps the most frustrating belief physicians encounter is that the larger a person is, the luckier, healthier, and happier that person will be. A fat person is perceived as healthy and fortunate, and a thin person is pitied as either ill or too poor to eat, both of which indicate a lack of good luck. Wealth is also partly attributed to luck because although each family develops similar economic skills, some are more fortunate than others. Some families enjoy good health, grow to a large size, and prosper, whereas others are plagued with illness, family troubles, and economic failure. In such a situation persons must take action to change their fate. Personal cleanliness, proper social attitudes, and behavior—generosity and virtue—should bring good luck. In a more general sense, traveling as opposed to living in one place is considered auspicious.

Marime, meaning polluted, defiled, or unclean, is used to indicate uncleanliness or impurity of a physical as well as a ritual or moral nature. To be "clean," the top half of the body from the waist up ideally must be kept separate from the bottom half of the body, which is considered polluted and is an area associated with feelings of shame.3 The source of pollution of the lower body is the genitoanal area and its emissions and secretions. Secretions from the upper half of the body are not polluting or shameful. For example, spittle is viewed as a clean and curative substance that may be used to clean cuts or scratches. This viewpoint conflicts with medical practice, which sees spittle as a possible source of contagion. Separate soap and towels are allocated for use on either the upper or the lower part of the body, and they must not be allowed to mix. Bathing in a hospital can be easily accommodated to Gypsy beliefs by providing them with separate soaps and towels for the upper and lower parts of the body.

A failure to keep the two sections of the body separate in everyday living can result in serious illness. A large number of practical guidelines are necessary to keep the upper half of the body separate and pure. At the least, it is important to wash the hands after touching the lower body and before touching the upper body. Body separation is a general cultural ideal that comes into play more in public situations than in private ones, and it has implications for a physician wishing to examine the lower body. Most Gypsy women will not agree to a gynecologic examination or a Papanicolaou smear unless the necessity of the procedure is clearly explained as essential to a woman's well-being.

*Marime* can also mean rejection because to become physically or morally impure could mean being rejected by the entire group. Rejection is a serious punishment for a Gypsy because it means social isolation.

#### **Marime** and Non-Gypsies

The use of marime as a defining term for a whole series of social boundaries gives it much importance for the Rom. The most important boundary is that between Gypsy and non-Gypsy. Because they do not observe body separation, non-Gypsies are a source of impurity and disease. Public places where non-Gypsies predominate such as public toilets, hospitals, buses, schools, offices, jails, and non-Gypsy homes are also potential sources of disease. All these places are less "clean" than the home of a Gypsy or open outdoor spaces such as parks and woods. When they must be in non-Gypsy places, Gypsies generally avoid touching as many impure surfaces as possible, but, of course, prolonged occupation of a non-Gypsy place such as a hospital means certain impurity. In this case the person tries to lessen the pollution risk by using disposable paper cups, plates, and towels—that is, things not used by non-Gypsies.

278 GYPSIES AND HEALTH CARE

#### **Age-Related Cleanliness**

Concern for a person's health begins at birth and is most active during the days or weeks of confinement (from 9 days to 6 weeks) of the mother. In the past, infant mortality for Gypsies has been high. This may be somewhat improved nowadays because more women give birth in hospitals; however, the crucial period of prenatal care is still entirely neglected because few women will accept a vaginal examination. One of the reasons Gypsies have turned to hospital birth is the advantage to them of avoiding the impure birth substances.

Gypsies recognize that a baby is vulnerable in the first weeks of life and take precautions to protect the child. A new baby is immediately swaddled tightly and handled only by his or her mother. The woman avoids certain foods, such as green vegetables and tomatoes, so that the nursing baby will not get colic. The child's navel is carefully cleaned and protected with ashes, and amulets are sewn into the baby's clothing for protection. In the first weeks at night, no member of the family is allowed to go in and out, and all windows and doors are kept shut lest a spirit of death, called "the night," enters to harm the baby. Crying and fear are prevented in a child by placing a small piece of johai ("ghost vomit," a curative substance) on their tongue. Visitors are carefully watched lest they give the baby the evil eye. If the baby fusses or becomes ill, the giver of the evil eye must make a cross with spittle on the forehead of the baby.

If despite these precautions a baby dies, this is bad luck for the parents. They must avoid the baby's body, which is buried in a secret place by the grandparents. Another way to avoid the bad luck of the death of a baby is to leave the funeral and burial to the hospital authorities.

After the period of pollution of birth has passed (more or less 6 weeks), children are considered basically pure in body and action. They can enjoy freedom from most social restraints and are not expected to understand or demonstrate "shame" in their actions. Physical contacts defiling to adults are not necessarily defiling to children, who need not take many of the precautions that adults do to ensure cleanliness in their daily lives. Children, for example, may eat food handled and prepared by non-Gypsies that postpuberty juveniles would reject.

At puberty, boys and girls are introduced to the idea of personal shame. Now both their bodies and their actions will be judged in terms of control of their own polluting secretions (menstrual blood, semen) and of "shameful" and polluting actions (sexual contact). The control of sexual relations and body cleanliness is modified by marriage and childbirth, but basically such controls last throughout married life until old age.

Women have a particular need to keep clean. Menstruation, for example, is surrounded by a number of rules to control the ill effects of this potentially polluting bodily function. When a girl first menstruates she is introduced to shame and must observe the washing, dressing, cooking, eating, and behavioral rules of adult women, partly for her own protection and partly for the protection of men. Her clothes must be washed separately from those of men and children, and she cannot cook food for others during menstruation. She must show respect to men by not passing in front of them, stepping over their clothes, or allowing her skirts to touch them

At old age, after menopause and when sexual relations

are assumed to have ceased, many of these regulations are relaxed. The aged are venerated and respected persons, both because they are politically powerful (political authority is vested in the aged) and because they now enjoy a "clean" status. When in contact with a group of Gypsies, it is always wise to seek out older authority figures and to communicate problems in their presence because they have authority and exert influence over younger Gypsies. Also, without the approval of older relatives, many young Gypsies will not agree to medical procedures considered risky.

#### Food and Health

Gypsies try to eat only food that is known to be pure and clean. Consequently, there are many regulations regarding the preparation and handling of food. There are no foods that are always prohibited, although some adult Gypsies fast on Fridays. Some foods—pepper, salt, vinegar, garlic, and onions—are considered lucky. To eat them encourages good health.

Eating together is imbued with great social significance. To share food with someone demonstrates respect, friend-ship, and acknowledgement of their cleanliness. Refusing to share food is a serious affront, implying a person is not pure and clean. The most serious punishment Gypsies as a group can impose on anyone is to refuse to eat with the person. To be prohibited commensality is social death. All rituals at which the Gypsies express important unifying social values involve the sharing of food at a feast.

All food must be carefully prepared to avoid any marime contacts. Cooking and eating utensils are always washed in a special separate basin reserved only for that purpose. In many households, a separate soap is reserved for food-related items, and even the hands are washed only with that soap before handling food. Women in birth confinement and menstruating women do not handle food. Food prepared by non-Gypsies is marime and is avoided. This avoidance is not always possible, such as when in a hospital, but it can be aided by eating wrapped take-away foods, drinking from cartons or bottles, and using disposable eating implements. Gypsies may simply eat with their hands rather than use utensils that may not have been properly washed.

#### **Causes of Illness**

Gypsies make a distinction between illnesses that originate from the non-Gypsies (gaje) and illnesses that are exclusively part of their own world. The former can be cured by non-Gypsy doctors, but the latter can only be tackled by the drabarni, their own medical practitioners. A knowledge of Gypsy medicine is the prerogative almost exclusively of the oldest women. They are both respected and feared because of this knowledge.

Gypsies do not have a scientific understanding of how the body functions. To them American physicians simply have a special knowledge of (gaje) illnesses and cures, a store of lore on medicines, and diagnostic and curing techniques. Not all physicians have the same knowledge or ability. To a Gypsy, a "big" doctor is one who cures, and a bad doctor is one whose medicine does not work.

Hospitals are feared and avoided whenever possible. Most Gypsies will go to a hospital only if they are in serious danger of dying or if they view the situation as a crisis. Furthermore, a hospital is a hostile place for the Gypsies, full of non-Gypsies, unclean, and completely removed from

#### TABLE 2.—Disease Causation and Treatment Disease Cause Cure Gaje (non-Gypsy) diseases Flu, "fevers," gonorrhea, syphilis, hernias, hemorrhoids Marime from contact with gaje; germs Avoid gaje; gaje physicians **Gypsy diseases** Mental illness: mental retardation Denial of cultural rules Observe cultural rules, such as marriage Grave illness, such as polio, serious influenza, pneumo-Mamioro, a spirit who visits places that are Johai ("ghost vomit"), Fuligo septica, a slime nia, and hemorrhages unclean and brings illness mold, is curative Tosca (nerves); convulsions O Beng, the Devil, the source of evil Khantino drab ("Devil's dung") or asafetida General illness and bad luck (prikaza) Mule, spirits or ghosts; not necessarily harmful, Prevented by showing respect to the dead; obbut Gypsies are afraid of them serving pomana (death ritual); avoiding places mule may visit; traveling

Gypsy society. Too few visitors are allowed, so for the Gypsies, who want to be with their kin when ill, a hospital is close to a state of exile from their own society. For these reasons, many Gypsies suffer great pain rather than go to a hospital. If they have to be admitted, the one thing they know for certain is that they do not want to be alone, to be without their relatives.

Gypsy and non-Gypsy diseases overlap, but their causes are different (Table 2). Most Gypsies prefer to try several different cures for any single illness to combat the different causes. A person who has convulsions, for example, may be rushed to a hospital where a physician can attend but will also be given asafetida by relatives. Physicians, therefore, are not in competition with Gypsy *drabarni*.

### **Health Status of Gypsies**

Many Gypsies claim that they are sicker now than they used to be. They believe it is because they travel less and live in houses instead of separate from non-Gypsies in camps. They think that the closer contact with non-Gypsies is having a deleterious effect on their health. Recent work on the medical condition of Gypsies would indicate that their medical problems are in fact serious. In a study of 58 Gypsies in the Boston area, Thomas found that 41 of 56 (73%) had hypertension, 24 of 52 (46%) diabetes mellitus, 32 of 40 (80%) hypertriglyceridemia, 26 of 39 (67%) hypercholesterolemia, 20 of 51 (39%) occlusive vascular disease, and 8 of 40 (20%) chronic renal insufficiency. A combination of diet, which is extremely high in fat, and genetics could be leading to the high cholesterol levels and hypertension. In this group, 50 (86%) smoked cigarettes and 49 (84%) were obese. The life expectancy of a Gypsy in the United States is between 48 and 55 years.5

To combat non-Gypsy diseases, the Gypsies logically turn to non-Gypsy physicians and hospitals. Although they are eager to try any cure that they think might work, they are suspicious of physicians and tend to "shop around." A physician who acquires the reputation of being effective will find Gypsy patients flocking to the office. Physicians whose Gypsy patients die under their care will probably never see another in their practice.

Surgery is feared, especially when general anesthesia is required, as Gypsies believe a person under anesthesia undergoes a "little death." Thus, Gypsies will gather around the bedside to muster support and help the patient come out of the anesthesia.

Despite their fear of hospitals, Gypsies are in general extremely knowledgeable of hospital procedure. They know what services are available and who are the best physicians

for specific problems. They learn of famous clinics and learn the complicated hospital regulations, how to get around them, and how to get what they want. One study concluded that Gypsies receive better medical care than other urban minorities because they have figured out effective ways to use medical services. In the same way that they are willing to try physicians and hospitals to cure them, they will also try cures and medicines advertised by Mexican *curanderos*, faith healers, and patented miracle cures. These are all *gaje* remedies. Nothing that might work is to be scorned.

Gypsy diseases have no connection with non-Gypsies or with germs and therefore cannot be cured by non-Gypsy physicians. For these diseases the Gypsies must turn to their own knowledge and their own medical practitioners, the *drabarni* (literally, "women who have knowledge of medicines"). The knowledge of spirits and medicines that old women have is a great source of power for them.

Serious Gypsy diseases are caused either by a spirit called *Mamioro* or the Devil. *Mamioro*, a specific spirit who has become a disease carrier, causes illness simply by visiting the homes of Gypsies. Fortunately, she only visits dirty houses, so by keeping a clean house, the Gypsy can keep her away. *Johai*, her vomit, is found most frequently in garbage dumps, and it is the most powerful and valuable cure the Gypsies have.\*

Several important diseases are caused by the Devil. *Tosca* is a disease that the Gypsies translate as "nerves." People who are nervous, fidgety, and worry excessively have *tosca*. A lot of Gypsies get *tosca*, especially the less aggressive and more sensitive ones who find it hard to keep up with the demanding, noisy, fast pace of Gypsy social life. *Khantino drab* will cure *tosca*. *Khantino drab* is also said to be found near the place where a person has been seized with a convulsion or epileptic seizure. It is believed that convulsions occur when a person is possessed by the Devil and that usually the Devil defecates during the convulsion. Locating the *Khantino drab* and giving it to the convulsed person will make the devil *marime* and drive him away.

#### Death

Gypsies can never be sure that they have done everything possible to keep pure, to promote auspiciousness, and in general to live up to the ideals of correct behavior; therefore, it is not surprising when someone becomes ill or suffers

<sup>\*</sup>Rena Gropper, PhD, Professor of Anthropology at Hunter College and a gypsiologist, discovered "ghost vomit" on some wood chips in her garden in New York City. Thomas H. Delendick, PhD, associate taxonomist at the Brooklyn Botanic Garden, identified it as a slime mold, Fuligo septica. A literature search showed that heretofore there had been no known economic or folklore uses of this slime mold (written communication, July 1983).

280 GYPSIES AND HEALTH CARE

misfortune. For the Gypsies, illness and death are not only a personal crisis, they introduce a social crisis as well. Reporters, physicians, hospital staff, social workers, and police are all aware of a great happening when a Gypsy becomes seriously ill and dies. When they ask what is going on, they may be told, "a Gypsy king (queen, prince) has died." This reply is a way of satisfying reporters and providing a reasonable explanation to hospital staff and police of why the Gypsies are flocking into town in large numbers, camping on hospital grounds, and in general breaking rules and creating havoc. Although there are no kings and queens, only leaders of the large Gypsy extended family, death is a major crisis in a Gypsy family that must be dealt with in ritual.

When a young person dies unexpectedly, the relatives are so grief-stricken that their behavior can become extremely wild. In one case, after the accidental death of a young man, the relatives were so distraught that they threatened physicians for "letting him die." The relatives scratched their faces, drawing blood, beat themselves on the chest and head, wailed, and screamed. This behavior was an expression of extreme grief. Even in the case of a death that has been anticipated, however, it is culturally acceptable for relatives to moan and shout out to the deceased, scratch their faces, or pull out their own hair.

Death at an old age is generally perceived as part of the natural and acceptable course of events, and the attitudes and feelings toward the death of an old person are very different from those toward early death. The main preoccupation of the relatives of an old person, as well as the dying person, is to see that all preparations for the person's eventual demise have been arranged. For the Lowara Gypsies, Yoors said, "the Gypsies yearned for what they called 'a great death' for which they could prepare and which they could share with their households, relatives and friends. They feared most that kind of death which came when one was unprepared."

John Davis, also known as Rattlesnake Pete, had a "great" death. His funeral was the greatest spectacle since Big George Adams hired an entire movie studio to provide props for his funeral in Los Angeles. John Davis had a brass band playing Dixieland in the funeral cortege, a horse-drawn hearse complete with black enameled scrollwork and silver lanterns and drawn by two grey Appaloosas. His grave was a red-carpeted crypt with a chandelier inside in a grave site surrounded by full-sized statues of the Apostles. In front of the casket was a flower arbor with the words "Welcome to Heaven, John Davis," in gold letters. He also had flowers in the shape of his favorite fishing chair with a pole and line dangling into a flower-edged pool, the American flag, a clock with the time of his death, a car, an airplane, and a ship (because he liked to travel), a barrel of beer and beer mugs (he liked a drink), and a little white house (he was a property owner). The newspaper the next day ran a picture of the

funeral cortege with the caption, "Death of a Gypsy King" (Janet Tompkins, Contra Costa County Social Service, written communication, July 1976).

#### Conclusions

To help physicians and hospital personnel interact effectively with Gypsies, I have some specific suggestions.

- Older relatives have an important role in the decisionmaking process of a patient. Try to include them and treat them with the respect they are due as elders in the community. Older relatives can be of great help in ensuring the cooperation of younger ones.
- Gypsies can alternate rapidly between moods or styles of interpersonal interaction from extreme assertion to plaintive begging. Medical personnel should appeal to the strong desire of Gypsies to obtain the best medical treatment and assure them that cooperation will work best for them.
- English is a second language. Explain clearly without resorting to too many technical terms the procedures the patient will undergo. Then ask if there is anything that is against the patient's religion. If there is something they do not want done, explain why it is necessary for their health or allow them to forego it.
- Many Gypsies cannot read, but it would be a mistake to assume that they are therefore less intelligent. Read important instructions (particularly at intake) to a patient or ask a translator to read out loud to the patient. They are accustomed to dealing with complex bureaucracies and policies.
- Gypsies accept emergency measures more readily than they accept proscriptions to undertake changes in diet or lifestyle; however, instruction in long-term health goals is crucial. They need education on the connection between diets high in animal fats, heavy smoking, drinking, and no exercise and the health problems they cause.
- A Gypsy patient does not want to be alone and will be fearful and agitated if forced to be without family. Allowing some relatives in the room with the patient on a rotation basis will keep the chaos to a minimum. Allow someone to stay overnight with the patient. If the patient is dying, it is essential that relatives be allowed to be present at the moment of death.

#### REFERENCES

- 1. Sutherland A: Gypsies, the Hidden Americans. Chicago, Ill, Waveland Press, 1986
- 2. Sutherland A: Health and illness among the Rom of California. J Gypsy Lore 1992, in press  $\,$
- 3. Sutherland A: The body as a social symbol among the Rom, In Blacking J (Ed): The Anthropology of the Body. New York, NY, Academic Press, 1977, pp 375-390
- 4. Thomas J: Gypsies and American medical care. Ann Intern Med 1985; 102:842-845
- 5. Thomas J: Disease, lifestyle and consanguinity in 58 American Gypsies. Lancet 1987; 2:377-379
- 6. Salloway J: Medical care utilization among urban Gypsies. Urban Anthropol 1973; 2(1):113-126
  - 7. Yoors J: The Gypsies. London, Allen & Unwin, 1967